Outcomes for Caregivers of Post-Stroke Individuals with Aphasia vs. without Aphasia: A systematic review

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BACKGROUND

Aphasia is an acquired language disorder that can affect all modalities of communication, including speaking, listening, reading, and writing (ASHA, 2016). The most common cause of aphasia is stroke, which is an interruption of blood flow to areas of the brain, usually located in the left hemisphere, that influence language expression and/or comprehension. These communication difficulties, undeniably, impact the person with aphasia (PWA) and their overall quality of life before, during, and after the recovery process. However, the caregivers of PWA are not only an important part of the recovery process, but are indirectly impacted by the aphasia itself, defined by a concept known as third-party disability. According to the International Classification of Functioning, Disability, and Health (ICF), third-party disability describes the effect of an individual's health condition on a caregiver's disability (WHO, 2001). However, little research has been conducted to determine the impact of aphasia on caregivers, although one study has suggested that potential challenges may include changes in family members' communication (Grawburg, Howe, Worrall & Scarinci, 2013;Le Dorze & Brassard, 1995).

Understanding potential challenges and difficulties can provide insight into the impact on caregivers of PWA and how their outcomes may differ from caregivers of post-stroke individuals without aphasia (PWOA). In order to gain greater understanding about the effects of aphasia on a caregiver's quality of life and report these findings to professionals working with such individuals, a systematic review was conducted to focus on the outcomes for caregivers of PWA versus caregivers of PWOA.

RESEARCH QUESTION

What are the outcomes for caregivers of post-stroke individuals with aphasia versus without aphasia?

SEARCH STRATEGY

A systematic review analyzing the strain and burden of caregivers of individuals post-stroke with and without aphasia was published in 2006 and little information was found specifically regarding caregivers of PWA (Rombough, 2006). The current systematic review focused on literature published between January 2004 and February 2016 in order to avoid overlap with the previous systematic review and build upon the existing findings that specifically compare caregivers of PWA and caregivers of PWOA. The search strategy from the 2006 study was replicated and studies were drawn from the following databases: PsycInfo, CINAHL, and PubMed. Out of 305 total results, two studies met the inclusion criteria, one being the previous systematic review from 2006 and the other being a qualitative outcomes study also published in 2006. The articles that met the inclusion criteria were both derived from CINAHL. No relevant articles were found from the PsycInfo or PubMed databases. All three researchers independently appraised both articles and assessed them for overall quality to determine eligibility for inclusion. After appraising the two articles derived from CINAHL, only one was found to be applicable towards the proposed research question, since the systematic review from 2006 did not yield any articles that included caregivers of PWA. However, because of our limited search results from all three databases, the systematic review was still utilized as evidence for further research in this field.

QUALITATIVE ANALYSIS (Bakas, 2006)

The qualitative analysis compared the differences in perceived task difficulty, depressive symptoms, and other-stroke related outcomes between family caregivers of aphasic and non-aphasic survivors at 1 and 4 months after stroke. A total of 159 family caregivers were assessed, with 46 in the aphasic group and 113 in the non-aphasic group. The following formal measures were given to both groups of caregivers: the Stroke Specific Quality of Life Scale Proxy Version (measuring communication, mobility, and self-care problems in stroke survivors as rated by their caregivers), the Oberst Caregiving Burden Scale (measuring caregiver perceptions of task difficulty), the Patient Health Questionnaire Depression Scale (measuring depressive symptoms experienced by caregivers), the Bakas Caregiving Outcomes Scale (measuring stroke-related caregiver outcomes, such as perceived changes in social functioning, subjective well-being, and physical health). Only caregivers in the aphasic group were given the Revised Memory and Behavior Problems Checklist Upset Subscale, measuring caregiver reaction to problematic behaviors in dementia and stroke. Based upon the demographics and the large proportion of female caregivers represented in the study, caregiver gender and caregivers of self-care deficits were added as additional independent variables, through subsequent analyses, and compared along with time (1 month post-stroke versus 4 months post-stroke) and group (aphasic versus non-aphasic).

Outcomes Rated as Moderate, Very, or Extremely Difficult or Upsetting, or Changing for the Worst, by > 20%: Caregivers in Aphasic Group

Difficult Caregiver Tasks	1 Month (N=46)	4 Months (N=42)
Communication with Survivor	54.3% (N=25)	47.6% (N=20)
Managing Behaviors	45.7% (N=21)	38.1% (N=16)
Managing Finances	32.6% (N=15)	26.2% (N=11)
Talking with Health Professionals	32.6% (N=15)	___

Worst Caregiver Outcomes	1 Month (N=46)	4 Months (N=42)
Time for Social Activities	84.8% (N=39)	71.4% (N=30)
Time for Family Activities	73.9% (N=34)	54.8% (N=23)
Level of Energy	52.2% (N=24)	50.0% (N=21)
Financial	52.2% (N=24)	42.9% (N=18)
Emotional	50.0% (N=23)	47.6% (N=20)
Roles in Life	50.0% (N=23)	42.9% (N=18)

The results showed that after adding female caregivers and caregivers of those with self-care deficits as covariates, the only noteworthy difference was survivor communication, which was rated more severely for caregivers in the aphasic group. Caregivers of PWA did have more negative stroke-related outcomes, but these findings were no longer significant in subsequent analyses, suggesting that caregiver gender and survivor self-care were more strongly associated with caregiver outcomes than the presence of aphasia. Additionally, because of numerous limitations, it is difficult to determine the validity and reliability of the results assessing differences in perceived task difficulty, depressive symptoms, and other-stroke related outcomes. Regardless, these discrepancies observed between different groups in this article still supports the need for individualized assessments and interventions for caregivers.

SYSTEMATIC REVIEW (Rombough, 2006)

This systematic review aimed to identify the relationship between primary caregivers' burden or strain and caring for stroke survivors with or without aphasia. Two search strategies were conducted across three databases, with the second search strategy identifying articles that compared caregivers of PWA and PWOA. The following three databases were searched for articles published during specific time periods: Cumulative Index to Nursing and Allied Health Literature (CINAHL) from 1982 to November 2004, Medical Literature Online (MEDLINE) from 1966 to October 2004, and Psychology Information (PsycINFO) from 1967 to October 2004. The exclusion criteria included editorials, letters, non-English and non-peer reviewed articles, non-stroke individuals, and caregivers for cancer/HIV patients. The first search strategy yielded 14 relevant articles (12 quantitative articles, 1 mixed-design, and 1 qualitative) while the second search strategy yielded 15 irrelevant articles. It was noted that, among the included articles, methods for measuring caregiver burden and strain varied between the 14 included studies. Researchers of these studies focused on 6 formal assessments, and one qualitative study utilizing 7 open-ended questions to assess caregiver burden and strain. The results revealed many inconsistencies within the field of research. The lack of relevant articles regarding aphasia makes this systematic review inapplicable towards the proposed research question for the present systematic review.

DISCUSSION

As previously mentioned, there is a clear lack of high-quality research comparing outcomes for caregivers of post-stroke individuals with and without aphasia. This may be, in part, due to the fact that there is no standardized assessment measuring the many facets of caregiver quality of life. Based on the low quality and limited availability of research in this area, it is difficult to confidently judge the differences in experience between caregivers of PWA and those of PWOA. Nevertheless, the 2006 study by Bakas found that caretakers of PWA experienced more negative outcomes in regards to time with family, social activities, level of energy, emotional well-being, roles in life, and physical health. While this data is immature, it does lend itself to the idea that there is a need for further research comparing these two groups, as well as research that focuses specifically on caregiver quality of life. Additionally, the development of a universal and reliable assessment to measure the multiple facets of caregiver burden, strain, and quality of life may be useful in providing a basis for research in this area. The findings from this review also offer strong implications for the ways in which speech-language pathologists work with and counsel caregivers of PWA. A universal assessment for caregiver quality of life could also provide insight as to how SLPs and other professionals can better assist and provide resources to caregivers in the stages following a stroke, and how these accommodations may differ depending on whether the person they are caring for also has aphasia.

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